Retinoblastoma is a type of eye cancer that starts in the retina. The retina is the layer at the back of the eye that detects and senses light.

Retinoblastoma can occur in one or both eyes, and mostly affects infants and young children under three years of age.

Children who have cancers in both eyes or multiple tumours in one eye at the time of diagnosis have an underlying genetic cause for the cancer.

**Chance of a cure**

One of your biggest concerns on learning your child has cancer may be about their chance of being cured.

Due to major advances in treatment, many children treated for cancer now survive into adulthood. On average, children diagnosed with cancer between 2004 and 2012 had a 5-year survival rate of 85%. In the 1980s, the 5-year survival rate for all cancers was about 73%.\(^1\)

Talk to your child’s doctor about your child’s diagnosis, treatments and long-term survival. Long-term survival is also called the outlook or prognosis. It depends several things, including:

- type of cancer your child has
- age of your child at diagnosis
- extent or stage of the cancer
- how the cancer cells look under a microscope (the shape, function and structure of the cells)
- how the cancer responds to treatment
- cancer or tumour biology, which includes
  - the patterns of the cancer cells
  - how different the cancer cells are from normal cells
  - how fast the cancer cells are growing.

To learn more about survival for retinoblastoma in children, visit [Australian Cancer Childhood Statistics Online](https://cancerqld.blob.core.windows.net/content/docs/Childhood-Cancer-in-Australia-1983-2015.pdf).

**References**


**Clinical trials**
It’s possible that your child may be able to be part of a clinical trial. Clinical trials are research investigations to test new treatments, interventions or tests, or as a way to prevent, detect, treat, or manage various diseases or medical conditions. The patients involved in clinical trials are volunteers.\(^1\)

With regard to cancer, researchers run clinical trials to test new ways to:

- treat cancer
- find and diagnose cancer
- manage cancer symptoms and treatment side effects.

If a trial is available, taking part in one will be entirely the family’s decision.

It’s important to note that any new treatments are strictly regulated and must be approved before they can be used in a clinical trial. Your child’s doctor will explain everything about the trial and give you detailed written information. If you wish your child to be part of the trial, you will need to give permission.

Participating in a clinical trial may or may not directly benefit your child. However, the results of clinical trials today help children with cancer in the future. If you’re interested in participating in a clinical trial, ask your child’s doctor if there are any suitable for your child.

You can find further information on our Clinical trials and research page.

References


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**Diagnosis**

When your child is diagnosed with cancer, it can feel overwhelming. This phase involves finding out if your child has cancer and determining the type of cancer they have. Children’s cancer can be difficult to diagnose as many symptoms are similar to those caused by less serious conditions or injuries. This means that your child may need several tests and medical appointments before you receive confirmation that your child has cancer.

If your doctor thinks your child has retinoblastoma, your child will have several tests, including a:

- Medical history and physical exam
- eye exam
- blood tests
- medical imaging, such as
  - ultrasound of the eye
  - computed tomography (CT) scan
Our section, How is cancer diagnosed? explains these tests in more detail.

Staging

Doctors use staging to describe how much the cancer has grown. Some of the tests will also help to stage the tumour. Staging determines:

- Where the tumour is
- How big the tumour is
- What nearby tissue it affects
- If the cancer has spread to other parts of the body

Your doctor will use this information to determine the best way to treat the disease. Staging will also give your doctor an idea of how well these treatments are likely to work (prognosis).

How doctors assess the stage or extent of disease varies. They use a combination of scans, blood tests and examination of the back of the eye to determine the stage. If the eye is removed, this is also used to determine the extent or stage of the disease.

The American Cancer Society describes other systems for staging retinoblastoma.

Risk factors

A risk factor is anything that increases a person’s chance of getting a certain condition or disease. Researchers know about some risk factors that increase the chance of developing cancer. However, for most children with cancer, the cause is unknown.

What we do know is that if a child develops cancer, it’s not because of something they, or their parents did to cause it. No one is to blame if a child develops cancer.

Even if your child has a risk factor, it doesn’t mean they will develop cancer. Many children with a risk factor will never develop cancer, while others with cancer may have had no known risk factors. Even if
a child with a risk factor develops cancer, the risk factor may not have had much to do with it.

Researchers don’t completely understand what causes retinoblastoma. Children with a positive family history of retinoblastoma are at high risk of developing this cancer.

**Family history**

Retinoblastoma develops because of abnormalities in a specific gene called RB1. This faulty gene can run in families, or it may develop for the first time in the child. About one in three children have retinoblastomas that run in families.  

References


**Support and more information**

A diagnosis of cancer in a child is difficult time for all involved. It’s normal for you and your family to feel overwhelmed, scared, anxious or angry.

If or others around you are having trouble coping, make sure you speak to your child’s treatment team. They have helped and supported many other families who have been through what you’re currently going through. Sometimes just letting other people know how you’re feeling helps you feel less alone. If you feel supported, then you will feel more able to support your child.

Most children’s hospitals will allocate a social worker to each family to provide support throughout treatment. If you need support, contact your hospital-based social worker to let them know how you’re feeling and to see what support can be made available to you and your family, including music therapists, play therapists or education support staff.

The following webpages and organisations also offer support and/or extra information for children with cancer and their families:

- **Living with children's cancer** has information about physical, emotional and practical issues during and after diagnosis and treatment.
- **Organisations** that can provide support and information.
- **Redkite** is a national organisation that provides emotional support, financial assistance, information and resources to families who have a child with cancer. You can reach them through their support line **1800 733 548 (1800 REDKITE)**, which is open (9am-7pm AEST),
email support@redkite.org.au or live chat on www.redkite.org.au

- **Canteen** provides a service called Canteen Connect, an online community for young people aged 12-25 dealing with their own or a close family member’s cancer, and **Parent Connect**, an online community with resources, information and peer support on parenting through cancer. Online counselling is available seven days a week, including evenings. Visit [https://canteenconnect.org/](https://canteenconnect.org/) or call 1800 835 932.
- The **Cancer Council** in your state or territory can give you:
  - general information about cancer
  - information on resources and support groups in your area.
- You can call the Cancer Council Helpline from anywhere in Australia on 13 11 20.
- Any of the major **children’s hospitals and networks** in your state or territory can provide information about childhood cancer.

For more information about childhood retinoblastoma, see:

- **Retinoblastoma**, from the American Cancer Society
- **Retinoblastoma treatment (PDQ®)**, from the National Cancer Institute (United States)
- **Retinoblastoma**, from Rare Cancers Australia.

Note that information from international organisations may not always apply to children in Australia.

## Symptoms

A few rare conditions can cause the symptoms and signs listed below, not just cancer. If your child has any of these symptoms or signs and you are worried, visit your child's doctor. The earlier cancer is found, the better.

Symptoms of retinoblastoma may include:

- a pupil (the black part in the middle of the eye) that appears white instead of red when a light is shone into it (e.g. in a photograph)
- a red or painful eye
- an eye that is larger than usual
- cloudiness in the iris (the coloured part of the eye) and the pupil
- eyes that seem to be looking in different directions (also called 'lazy or crossed eye').

## Treatment
Your team of doctors, called a multidisciplinary team (MDT), will care for and treat your child, and will ensure that all your child’s needs are considered while they have cancer treatment. The section called The treatment team has further information about this.

Treatment for retinoblastoma depends on:

- the age of your child
- the size and stage of the cancer
- other factors.

Doctors will suggest treatments based on your child’s situation. Treatment may involve one or more of the following:

- surgery
- chemotherapy
- radiation therapy
- Laser therapy or cryotherapy (freezing the tumour)

**Surgery**

Your child may have surgery to remove the entire eye and part of the optic nerve. This is called enucleation. This is required if the tumour:

- has damaged your child’s eye so much that there is little or no chance they would be able to see again
- is large
- has not responded to treatment (called refractory)

It might also be necessary for such surgery if the tumour has come back after treatment (called relapse). Later after the wound has healed, the doctors will put in an artificial eye or implant in the eye socket to take the place of the eye. This is attached to the eye muscles so it can move. A life-like layer can be added to the surface to make an artificial eye.

See [How is cancer treated – surgery](#) for more detail about cancer surgery.